

POLIO NSW INC *formerly Post-Polio Network (NSW) Inc*

NETWORK NEWS

Incorporating – Polio Oz News

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100th Issue of Network News

In July 1988, New South Wales people who had contracted polio in past years attended their first-ever Seminar/Workshop on the Late Effects of Polio. On this day the seed was sown to grow Post-Polio Network (NSW) Inc, which was subsequently renamed to Polio NSW Inc in 2011.

In November 1988, Issue No. 1 of the Post-Polio Network Newsletter was written by the Convenor of the Working Committee establishing the organisation, Laurie Alsop. From two-and-a-half foolscap pages, *Network News* has grown to over twenty A4 pages and has incorporated Polio Australia's newsletter, *Polio Oz News*, since issue No. 80. Below you will be able to read the very first newsletter from November, 1988.

The first two newsletters were written by the Convener, later President, Laurie Alsop. Gillian Thomas, our current President, took over as editor from Issue No. 3 in 1989 and continued until issue No. 80 in 2012. Gillian grew *Network News* to a very informative journal, containing regional, NSW and Australia-wide content, together with overseas material of interest. Members' articles, stories and letters were also a feature of the newsletters.

To enable Gillian to give more time to Polio Australia, Sue Ellis and Nola Buck took over as Co-editors in May 2012 producing issue No. 81. They endeavour to continue the high standard set by Gillian – keeping members and health professionals up to date with the latest information on the late effects of polio, as well as generic disability information. It must be noted that Gillian continues to be the final 'polisher' of *Network News*, contributing from her vast knowledge to ensure the quality of the newsletter and adding current information as needed in her President's Report. We would not be where we are today without Gillian's vision, dedication and determination.

Sue and Nola wish our readers many pleasurable and informative hours of reading of this our 100th edition of Polio NSW's *Network News*.

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POST POLIO NETWORK NEWSLETTER

On the 2nd July, 1988, a Seminar/Workshop on the late effects of Polio was held in Sydney. Several years ago, in the United States, people who had contracted polio 30 and 40 years ago began to notice symptoms such as undue fatigue, muscle and joint pain, respiratory problems and muscle weakness occurring. These symptoms became known as the post-polio syndrome. Although research to date has produced no conclusive data as to the cause of this syndrome, it appears that the problems are likely to be linked to polio. Thousands of polio survivors in the United States were reporting similar symptoms, and all were experiencing problems in having their symptoms taken seriously.

Polio survivors in Australia were also experiencing similar symptoms and the same lack of understanding of their problems.

In 1987 a number of Australians attended the Fourth International Polio & Independent Living Conference in St Louis, U.S.A. Some eight hundred people from around the world were present, all of them having symptoms of the syndrome. It seemed that too many people were experiencing difficulties for it all to be in their "imagination".

Those returning to Australia felt that attention must be drawn to the possible late effects of polio and that information should be provided to the many people who had contracted polio during the epidemics of the 30's, 40's and 50's.

It was decided to hold a Seminar on the subject, and to invite Professor Irving Zola, a member of the International Polio Network, and himself a polio survivor. The Seminar provided the first opportunity in many years for people with polio to get together. It was discovered during the course of the day, that most of those present were experiencing symptoms identified with the syndrome.

The major recommendation from the Seminar was that a Post Polio Network be established, with the following aims:-

1. Provision of up-to-date information on the late effects of polio
2. Establishment of a support group for post-polio survivors
3. Establishment of an information base
4. Encouragement of research into the Post Polio Syndrome.
5. Organisation of Seminars on the Post Polio Syndrome

A Working Committee was elected to pursue these and other recommendations from the Seminar.

The Workshop inspired a great deal of media interest, including articles in the Sydney Morning Herald and coverage on the national radio show, Health Report. As a result, enquiries were received from across Australia. There are now plans to establish similar post-polio support groups in Victoria and South Australia.

Following the Seminar/Workshop, the Working Committee has met twice and has prepared the enclosed questionnaire. We would appreciate your co-operation in completing it and returning it to the Convenor, c/- of The New South Wales Society for Crippled Children, P.O. Box 4055, Parramatta, N.S.W. 2150.

The questionnaire will help assist the Working Party to establish a Network that will meet your needs.

Also enclosed is a Survey "Polio Survivors & Their Health", prepared by Dr Mary Westbrook. Again, we would appreciate your co-operation in completing it and returning it to Dr Westbrook at the address shown at the bottom of the survey form.

The possibility of producing a regular newsletter has been discussed. This would contain articles on the syndrome, methods which may assist in relieving its symptoms and information on useful contacts. We would also like to hear of your experiences and solutions you may have found that have helped you to deal with the Syndrome. We would very much like the group to be a self-help network. After all, as one participant said during the Seminar, "we have outlived most of our doctors and carers". In many cases, we have had to find our own solutions to the difficulties we are experiencing, and we should continue to help ourselves and others by sharing this information.

So to start the information sharing here are several items:

* The Fifth International Polio Conference will be held in St Louis, U.S.A. from May 31 to June 4, 1989. Apart from providing up-to-date information on the management of post-polio, there will also be an exhibition of the latest aids and equipment for people with disabilities. We will bring you more information about the Conference as it becomes available.

* A useful journal, which often contains articles on Post Polio is the Rehabilitation Gazette, published by Gazette International Networking Institute (G.I.N.I.), 4502 Maryland Avenue, St Louis, MO 63108, U.S.A. Subscription is \$25.00 (U.S.) per year to individuals.

* The August/September Supplement to Breakthrough contains information on the Post Polio Syndrome in a convenient pull-out form. Free copies of Breakthrough are available from G.P.O. Box 9848, Canberra, A.C.T. 2606.

The Network has begun to compile a list of articles on the late effects of polio. We would be interested to hear about any articles you may have. We would then publish these references in the Newsletter.

-The International Polio Network (an organisation which provides information of interest to post-polio survivors is located at 4502 Maryland Avenue, St. Louis, MO.63108, U.S.A.

Please share this information with other people you may know who have had polio.

One of the most important things that came out of the Post-Polio Seminar/Workshop was the feeling for so many of us that at last we are no longer isolated from each other in our experiences. What a relief to know that "I'm not the only one who has this after all".

We look forward to your comments and ideas, and to working together to build a strong self-help network.

LAURIE ALSOP
CONVENOR

Late Effects of Polio Clinical Practice Workshops Coming to NSW

Polio Australia conducted a very successful series of Clinical Practice Workshops during 2015/2016 in Sydney's northern region. These Workshops resulted in 140 health professionals expanding their knowledge of, and clinical skills in, diagnosing and managing the late effects of polio. Polio Australia has now received Federal Government funding over three years to conduct a pilot program of similar Workshops throughout Australia, and has employed Paul Cavendish as the Clinical Health Educator. For Polio NSW members, this means that both a Sydney metropolitan and a NSW regional Workshop series can be held each year, educating an expected total of 600 health practitioners by the end of the pilot. Paul commenced with Polio Australia on 11 August and, in consultation with the various State Polio Networks, will shortly begin mapping where the Workshops will be held. Further information on this wonderful initiative will be in the next *Network News*.

Virtual Mindfulness

Expressions of Interest now open for pilot program participants

Virtual Mindfulness, a crowdfunded community project supported by Polio Australia to help relieve everyday disability pain and strains, is now seeking expressions of interest from potential participants for a pilot program.

In association with Breathworks, a leading international provider of clinically proven mindfulness techniques for health, the pilot will be trialing the use of innovative online tools to help polio survivors learn (from the comfort of their own homes):

- How to manage pain, illness and fatigue in daily life.
- How to breathe into the present moment and find choice.
- Breath and body awareness.
- Gentle mindful movement and relaxation.
- Mindfulness meditation practice, including cultivating kindness towards yourself and empathy for others.

Running over the course of 8 weeks (approx 2.5 hours per week), participants will be learning within a small, supportive and friendly group setting. Places are strictly limited to 8 people and a fee to cover course materials and postage/handling of \$75 applies. For logistical purposes, participants must also be residents of Sydney.

About Mindfulness

Mindfulness uses meditation techniques to help relieve pain and suffering. Rather than only targeting one specific aspect of a person's suffering, mindfulness helps deal with associated stresses and its effects on a person's overall quality of life. There are many peer-reviewed scientific papers to prove the effectiveness of mindfulness in reducing pain and enhancing the mental and physical well-being of people. Many hospitals and medical professionals now also prescribe mindfulness techniques to help patients cope with suffering.

Further Details

For enquiries, please contact: christopher_tia@yahoo.com
For further Information, please visit:

* **Virtual Mindfulness Project** – startsomegood.com/virtualmindfulness

* **Breathworks** – www.breathworks-mindfulness.org.uk

Swelling and Polio Survivors - Why we need to take it seriously

By Dr William DeMayo, MD – DeMayo's Q&A

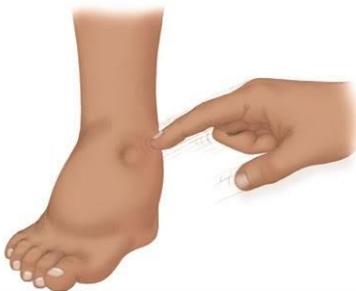
This article is published with permission from Pennsylvania Polio Survivors Newsletter, July 2017 www.papolionetwork.org.



Question: Dr DeMayo – My right leg has always been very thin. It's now terribly swollen from the knee down, and feels extremely heavy (I'm having trouble transferring into the shower). The doctor did an ultra sound to rule out blood clots. It was negative. I've been using a power chair for 18 years. What should I do?

Response: This is a great question that pertains to many polio survivors. Before addressing the issue of swelling itself, I want to acknowledge and endorse the evaluation of unilateral swelling with ultrasound to rule out blood clots (Deep Venous Thrombosis-also known as DVT). Given that a DVT in the leg can break off and travel through the heart to the lungs, it is a potentially life-threatening condition that is easily diagnosed using this technology that involves soundwaves (like sonar). Venous clots are most common in someone who has recently become sedentary or has had an injury followed by unilateral swelling. Although they are less common in the chronic setting, it is a diagnosis that should never be missed. This reinforces the general concept in healthcare management to be sure and rules out the most serious causes, especially if diagnosis is easy. It is also important to rule out other common causes of swelling such as congestive heart failure or kidney failure but these typically present with swelling in both legs. Unilateral swelling can also infrequently be caused by issues such as tumor obstruction to blood flow. In any case, it is always important to discuss swelling with your physician before concluding it is benign.

With the above said, the most common cause of swelling in polio survivors is “dependent edema”. Swelling in the feet and lower legs accumulates due to gravity. The heart pumps fluid to the feet, but physical activity needs to pump the fluid back. Contracting muscles literally squeeze the blood in veins towards the heart and valves prevent the blood from moving back. Any immobility, paralysis, or sedentary behavior will limit this pumping action. Fluid from the accumulating blood seeps into surrounding tissues leading to edema.



The extent of edema in the tissue is assessed by pressing for several seconds and evaluating if “pitting” of the tissue occurs where fluid is pressed out of the area. The more pitting there is, the more severe the problem. Treating lower extremity edema centers around minimizing the effect of the three biggest factors that exacerbate swelling: **S**itting, **S**edentary lifestyle and **S**alt.

- **S**itting

Gravity makes it more difficult to return fluid to the heart and increases the chances that edema will accumulate in the legs. The lower the feet are relative to the heart the greater the hydrostatic pressure that needs to be overcome and returning blood to the heart. Furthermore, resistance at the knees and hips in a bent sitting posture can make this return of blood even more difficult. Unfortunately, the opposite is also true if the feet are at the level of or above the level of the heart then it is easy for fluid to return. Most people wake up with less edema in the morning. Elevating the feet above the heart as much as possible will result in further reduction in swelling. **I**f there are no heart problems or other

contraindications, a brick under the foot of the bed, can result in fluid slowly moving out of the feet into the general circulation over the course of the night so it can be excreted by the kidneys. The effect of this small elevation can be illustrated if one thinks of water on a flat surface; it doesn't take much elevation of one side to get the fluid to flow to the other side. The slight elevation is compounded over the long duration we are typically in bed at night.

During the day, support socks/stockings can often help prevent fluid from accumulating when an individual is sitting. Support stockings can range from over-the-counter support



socks from Walmart to custom stockings prescribed by a physician. Donning these socks can be problematic. This is especially true if there is upper extremity weakness. A sock-aid is a plastic sleeve with a rope pull that can be quite helpful. Despite this aid, many people abandon compression socks as being impractical. I have always found Tubigrip to be a helpful alternative to stockings - it is a tubular bandage that has enormous elastic qualities. A double layer from the toes to the knees is usually easy to slide on and well-tolerated. Moderately severe swelling usually requires size E. A roll can be obtained on the Internet through Amazon. Some providers also sell it by the yard.



For individuals who do not respond to static compression sequential compression pumps are available by prescription (see your doctor). In some cases, these devices can be very helpful. They involve use of an inflatable "boot" with several chambers. A pump inflates the chambers in the foot, then the ankle, then the lower leg pushing fluid back towards the heart. Treatment usually takes a couple of hours a few times a week.

For those who are using a power wheelchair, lower extremity edema can be dramatically improved with a "tilt in space" option. A "tilt in space" option requires specific medical documentation to be provided to the insurance company. As the head and upper body move down, the feet are raised and the hips and knees are maintained at 90°. This is very different than reclining (when the feet stay at floor level). Tilting periodically throughout the day can drain fluid from the feet and dramatically prevent accumulation.



- **Sedentary Lifestyle**

Many polio survivors have significant impairments in mobility. For those who are able to walk, even short walks multiple times per day can be of significant benefit in preventing swelling. While walking is clearly the best activity to facilitate muscles pumping fluid back to the heart, any contraction of these muscles will help. "Ankle pumps" are exercises that



are often taught to all patients on rehabilitation units to prevent swelling and clots. They can be done in bed or wheelchair and simply involve forceful contraction of the calf muscles while pointing the toes down followed by pulling the toes up towards the body and repeating multiple times throughout the day. It is helpful to think of this like pumping the

handle on a well to move fluid. Many polio survivors with severe atrophy in the lower leg may simply not have the muscle mass to "pump" the fluid. If atrophy is only in one leg, it is typical to see swelling mostly on that side.

- **S**alt

Kidney failure leads to swelling because salt is not excreted in the urine. To keep the concentration of salt normal in the body, we then retain more fluid to dilute the salt. Most of us, especially as we get older, can see this impact even without kidney failure. Eating salty chips, soup, or other foods high in sodium can dramatically affect edema for many individuals. Evaluating sodium intake is the first step in preventing this. Talk to your doctor if the swelling continues. Physicians may recommend a "Water Pill" (Lasix, hydrochlorothiazide, or others). If one is prescribed, it is best taken in the morning to avoid interfering with sleep.

Leg swelling is more than a cosmetic issue or inconvenience when donning shoes and socks.

Edema can reduce blood flow to the skin and increase the chances of infection. Additionally, the sheer weight of the fluid can severely impair function in individuals who already have weakness. Excess fluid in the legs can add up to 10 or 20 pounds of "deadweight" and lead to fatigue over the course of the day or inability to climb stairs, transfer into the tub, or get in a car. Think about the impact of putting 10 pound weights on one's ankles for the entire day. Furthermore, over weeks and months this can also result in functional decline leading to a more sedentary lifestyle and a vicious circle. Conversely, removing a significant amount of edema can often improve function. A minor amount of swelling is very



common and may not be problematic but moderate or severe swelling is almost always important to address with your physician. For cases that did not respond to the above suggestions, Lymphedema clinics are available. My experiences have been that many of these clinics provide short-term benefit with edema returning after treatment concludes. If, however, they can get swelling down so that compression stockings can be used then long-term management can be achieved.

I encourage Polio survivors to continue to pursue treatment of moderate or severe edema (swelling) until a customized approach is developed that meets their needs. In most cases that includes a combination of approaches with input from a treatment team including a rehabilitation physician, primary care physician, therapist, and nurses.

[Editor's Comment: Mt Wilga Private Hospital has a Lymphodaema Clinic available alongside our LEO P Clinic. It can give advice on compression stockings and leg pumps.]



Editor's note: We would like to apologise to Dorothy and the Wollongong Support Group for inadvertently omitting their details from our last newsletter.

AREA	WOLLONGONG
CONVENOR	Dorothy Robinson
PHONE	4271 8655
MEETING	12 noon every 2 nd month except January
PLACE	Illawarra Yacht Club, Northcliffe Drive, Warrawong



My Aged Care

Reprinted with permission from Arthur's Tas Polio News, July 2017. Editor and author: Arthur Dobson

The My Aged Care number is **1800 200 422**.

From the May issue of the Bayside Polio Support Group newsletter came the following article:-

Aids and Equipment:

Home care packages are not intended to be an aids and equipment scheme. However, some aids and equipment, including custom made aids, can be provided when they are identified in your care plan and the item can be provided within the budget available for the package.

Package funds can also be used towards a motorised wheelchair or motorised scooter. However, given the high cost of these items, it is expected they would be leased rather than bought.

The package funds are capped. Where possible, the cost of any aids and equipment must be met within the package funds. If there are not enough funds in the package, you will need to pay any additional costs.

If package funds are used to buy, or contribute towards the cost of, aids and equipment such as a motorised wheelchair or scooter, there needs to be clear documentation between you and the service provider as to:

- whether it is leased or who owns the item
- what will happen to it when you leave the package
- who is responsible for ongoing maintenance and repair costs.

The agreed responsibilities must be written down and included in your home care agreement.

You can also use state-based aids and equipment programs and access specialised aids and equipment schemes where there is a need for support.

<http://www.myagedcare.gov.au/help-home/home-care-packages/aids-and-equipment>

Did you know?

States and territories have agreed that aids and equipment can be accessed through their programs.

Clients receiving Individual Support Packages (ISP) may use ISP funding to lease, purchase (or part purchase) aids or equipment if:

- they are needed urgently
- the purchase of aids and equipment is already included in their Service Agreement prior to transition to the CoS Programme
- a State scheme does not supply the required aid or equipment
- a State scheme does not fully fund the purchase of the required aid or equipment.

Any purchase or lease of aids and equipment must be added to the client's approved ISP Service Agreement, and be in accordance with the CoS Programme Manual (Continuity of Support Program for people with a disability over the age of 65)

<https://agedcare.health.gov.au/aids-and-equipment>

Mid-Year Seminar Report

by Susan Ellis

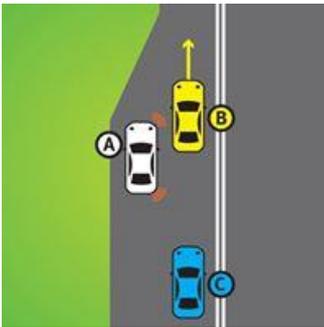
Tuesday 27th June 2017

Frank Higgins: Frank is a presenter for the NRMA's Older Driver Education Program "Years Ahead Driver Program".

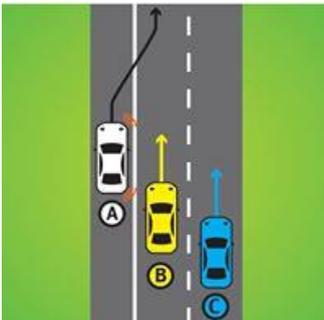
The NRMA has been around for about 90 years and most think of them as being around to fix up our cars when they break down, but there is a lot more involved with the NRMA than just doing road service. For example, in the last 12 months they have rescued about 2,500 babies from locked cars, and replaced 178,000 batteries in cars, but they have also worked with other issues. NRMA has lobbied for more car parking spaces at railway stations; they have also lobbied the government and the RMS to eliminate some of the speed cameras that really were just revenue raisers rather than for saving lives.

The presentation today will look at some road rules refreshers, safer driving tips, pedestrian safety, your health and how that affects your driving both physically and mentally, the new legislation relating to older driver licencing, and how to stay mobile.

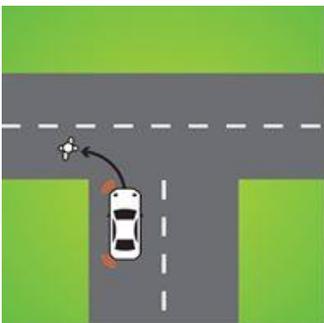
Road Rules Refresher:



Merging: The white car (A) has the right of way to merge in front of the blue car (C) because it is in front.... giving way to the right no longer applies.



Changing Lanes: When car (A) wants to change lanes, car (B) has the right of way so car (A) has to give way until the lane is clear and it is safe to do so.



Pedestrians: Who has the right of way? The new rule is that the pedestrian **always** has the right of way whether there is a pedestrian crossing or not.

Mobile Phones: You **cannot** use a mobile phone while driving except on one occasion – you can take your mobile off the 'cradle' and hand it to someone else, it's the only time you can have it in your hand.

U Turns: It is illegal to do a U turn wherever there is a fixed line. (You can however cross them if you are going into your driveway or a service station.) You must not make a U turn at traffic lights.

Parking: When there is a fixed yellow line along the kerb side of the road it means that you cannot park at any time, ie no stopping. If the lines are broken this means that there is restricted parking and there is usually a sign which states the times that parking is restricted ie a clearway, no parking between 6am and 9am.



School Zones: These 'dragon' image symbols appear about 32m from the school zone, there could also be someone with a 'lollipop' stick and/or flashing lights, leaving no doubt whatsoever that you are in a school zone with a speed limit of 40kph.

Roundabouts: Before roundabouts there were crossroads along with all the accidents which resulted. The whole idea of a roundabout was that if it is used correctly it will keep us safe. The roundabout will slow down all the traffic no matter which direction it is coming from or whether it is a minor or major road. Everyone has to slow down and give way to the first car in the roundabout NOT the one on the right. Always indicate where you are going ie indicating when you are leaving the roundabout when practicable.

Bicycle: When overtaking a bicycle you must be 1 metre away if you are driving up to 60kph or 1.5 metres away if you are driving over 60kph. It is the only time you can cross a double line IF you need to go around a bicycle.

The 5 Most Common Accidents:

1. Rear-ender – travelling too close to the car in front
2. Not obeying a STOP or give way sign
3. Misjudging the distance of the oncoming vehicle by turning in front of it and colliding
4. Running off the road
5. Colliding with an obstacle ie tree

(Points 4 & 5 are usually due to speed, fatigue, distraction and happen more often in country areas)

Blind spots: Every car has a blind spot and when changing lanes head checks are mandatory. So when going for an on-road assessment/test at 85, if you don't use your head for every manoeuvre it can be a serious fail item and that's going to go against you. Mirrors are not enough; you need to double check by turning your head to see what's around you. When it comes to backing out of driveways, if it is very difficult to see then perhaps it would be better to consider backing into the driveway so you can later exit safely front forward.

How to keep safe as a pedestrian: Accidents that occur on a pedestrian crossing are 50:50 the fault of pedestrian and driver. Older drivers make up 10% of the driving population but are involved in 30% of the accidents as a pedestrian. It is important to keep looking up when using a pedestrian crossing and observing what is happening around you, try and catch the drivers' eyes, don't assume they have seen you. This also applies when you are on a motorised scooter. Frank also mentioned that to keep safe on a scooter (or as a pedestrian) use the footpaths but if you have to use the road always travel against the traffic NOT with your back to the traffic.

Don't emerge between parked cars to cross the road. When crossing at traffic lights and the walk sign starts flashing halfway across don't start running, this is unsafe, there is ample time to get across. The red flashing sign is meant for the person who has yet to

leave the footpath, it tells them NOT to start crossing as they will not make it across in time. Don't use mobile phones when walking across pedestrian crossings. Also be aware of visual problems at sunset or at night or twilight. Can you be seen by oncoming cars?

Health and Driving: To keep safe you need to be in the best physical and mental health; hearing, vision, strength, flexibility. You need to be able to problem solve when you get into a bit of a predicament. Dementia is of great concern and should be reported to the RMS; if an accident occurs you may lose your insurance completely and could be prosecuted. There is a duty of care to report dementia. Signs of dementia might include misjudging speed or distance to turn, becoming angry, increased dents and scratches on the car.

A medical is required every year at age 75 to renew your driver's licence. At 85 you will also need to undertake a driving test every 2 years. However, if you have a modified licence ie where you drive within a 10km radius and not at night, then you are not required to do a driving test or assessment.

Other modifications: if you can't turn your head (you may have rotator cuff problems in your shoulder) then you can have extra mirrors installed to eliminate having to do a head check ie a car modification.

At 85 you can either go to the Motor Registry for a driving test or you can do a driving assessment which assesses your ability to drive your car and obey the rules. The registry driving test is free, you can have three attempts to pass after which you will fail. They will take you for the test around the area of the motor registry, it might be somewhere you are not familiar with which can be quite nerve racking. Whereas, the driving assessment is undertaken in your vehicle, around your streets where you are familiar and which makes you feel much more comfortable and less stressful. This comes at a cost, there are fees to pay to the 'assessor' who is usually a private driving instructor. You can attempt this assessment as many times as you like as long as there isn't a serious fail item or other driving problem. This process is usually less stressful than the Motor Registry driving test.

Frank recommends for people in their 80s who are really worried, concerned or scared about going for a driving assessment/test, to go for a few driving lessons. The instructor can see where you are doing well or where you need to do a little brush up before going for the official test/assessment.

Giving up your licence may have to happen; sometimes this might be only temporary due to a medical problem. Self-assessment is useful; how are you managing in traffic, has it become difficult, are you becoming slower reacting to dangerous situations, are you too sleepy while you are driving? If others start to comment on your driving skills don't brush them off, they are concerned about your safety so do something about it.

Other options to get around: use a scooter, taxi, public transport, car-pooling, local council services.



Kerry Highley: *Kerry grew up in the Sydney beachside suburb of Manly, and remembers with great clarity the first time she saw children with their legs in calipers, a memory that remains with her to this day. Her initial career was in medical laboratory science at Sydney's St Vincent's Hospital, a profession in which she worked for many years before returning to study History at the Australian National University in 2000. In 2009 she received her PhD in the History of Medicine for her thesis on the polio epidemics in Australia. Kerry spoke about her research into the epidemics and her book "Dancing in my Dreams: Confronting the Spectre of Polio".*

Polio is an ancient disease that has been around since the days of the Pharaohs. Early medical documents in Australia mention the presence of a mysterious disease characterised by marked paralysis of the limbs and sometimes the torso. It wasn't until 1885 when there was an outbreak in Port Lincoln, South Australia, that it came to be

officially categorised as infantile paralysis because it seemed to affect mainly children under the age of 5 years.

Kerry grew up in the seaside suburb of Manly which is a popular tourist attraction in Sydney but it is also the site of the Far West Childrens' Home, where kids from the bush were sent to convalesce from various illnesses including polio. This was where Kerry caught her first glimpse of children in braces and calipers and even though she was a toddler at the time she still remembers the image of the children sitting at the edge of the shore, where the waves were breaking, with their legs sticking straight out in front of them, bound in leather straps and steel rods. She remembers asking her mother "*what is wrong with these kids, why do they look like that?*" This was at a time before Salk, before the vaccine came in and parents were terrified of their children catching polio and so my mother replied "*Oh, come away don't get too close to those kids, you might catch something*". Of course we now know that this was impossible but it was part of the fear at that time. So it was this experience that planted a small seed in her brain which would germinate some forty years into the future when she started thinking about looking into the history of polio.

Soon after starting her research at ANU Kerry realised that she wanted to focus heavily on the experience of the polio survivor. For part of her research she travelled to the Minnesota History Centre in the U.S. to visit the Elizabeth Kenny's Archives. Minnesota was the first state in the US to welcome Kenny and to actually set up an institute in 1942 in Minneapolis where she could practise her treatment. When Kerry looked through hundreds of letters and files on Kenny and letters from patients, she found that there was this remarkable international community. In a large cross section of these recollections, these personal fragments actually spoke of the shared experience of polio that knew no borders, in other words the same people in the U.S. seemed to be experiencing exactly the same things as people in Denmark and Australia, the same sort of experience of contracting polio.



Telling the story of polio treatment in Australia also meant telling the story of two women, and these two women were Dame Jean Macnamara, who was a doctor in Melbourne and Sister Elizabeth Kenny. Macnamara followed the orthodox medical approach to paralysis by using splints, plaster casts and braces to protect and control the body before commencing therapeutic exercise, in other words, doctors would wait until all signs of the acute stage of the illness had passed before they would start exercising.

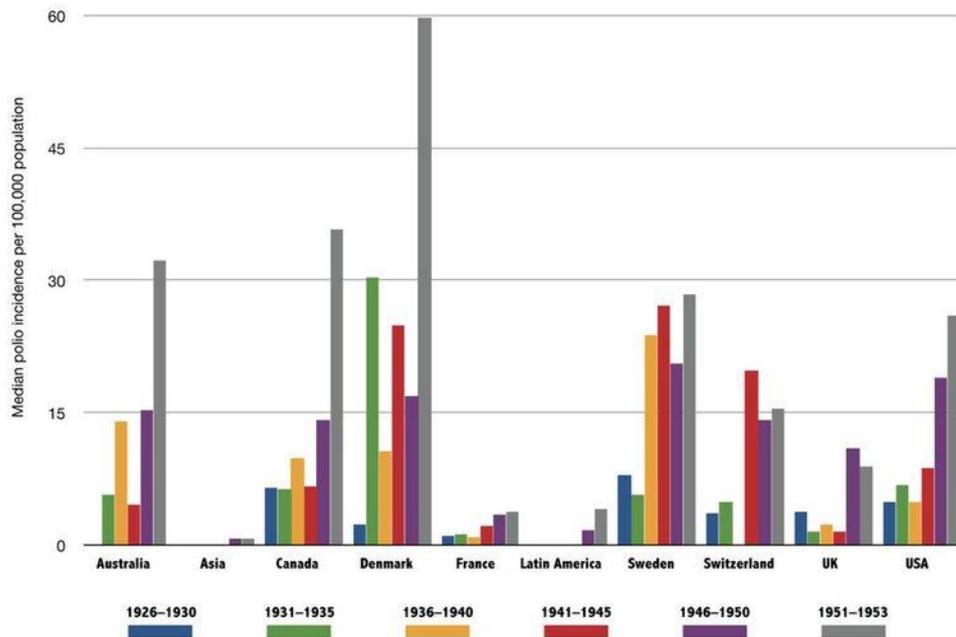
In her clinic in Townsville, Kenny endorsed and practised a method of treatment that was the exact opposite. Kenny believed in little or no form of constraint for the paralysed limbs or body and endorsed gentle stretching of muscles in the early acute stage of the disease. Kenny also used hot packs to relieve pain, spasm and tightness of muscles. Neither woman endorsed hydrotherapy but this was commonly used during the polio epidemics at the Fairfield Infectious Diseases Hospital in Melbourne. Kerry made note that the Kenny nurses wore blue uniforms instead of white, an idea that Kenny had to make the nurses look less frightening for small children.



Sister Kenny and Jean Macnamara symbolised the rift that existed between the accepted medical treatment and an alternative one. These polio epidemics highlighted the difference between the new and the old medical theories of practice. The epidemics generated a fierce debate in Australia and in the U.S. about the role of treatment in the care of the paralysed body and just who was qualified to prescribe and practise these new therapies.

But while Kerry was writing her book she wanted to try and tell the general public what it felt

probably the anxiety and apprehension of the grim reaper campaign of the 1980's to raise the awareness of AIDS and to scare the public into modifying the risk taking sexual behaviour that could lead to infection with the AIDS virus. The advertisement depicted the grim reaper standing in the shadows of a bowling alley waiting to take down unsuspecting innocent Australian, mothers with babies, young children and healthy young men. Unsuspecting is the key word here, people were afraid of contracting AIDS and no one felt safe and this is the way the Australian public felt during the years of the polio epidemics in the mid 20th century.



Source: WHO. In: Proceedings of the Third International Poliomyelitis Conference, Rome, 1954. 11

These statistics show that the anxiety that parents held about polio was not without foundation. Polio was the only epidemic disease to record an increased incidence in western countries in the 20th century. Following the war years the intervals between epidemics in Australia became shorter thus indicating that the character of the disease had changed and polio was becoming endemic, in other words it had become localised within the country.

Earlier polio researchers were on the whole unwilling to let go of the entrenched ideas they had about the association between dirt and disease. Everybody knew that the two went hand-in-hand, but in fact this wasn't the case with polio. The reluctance of experts to accept that polio also affected children and adults in clean, healthy environments with good sanitation, was a major factor in the failure to recognise that the polio virus was and remains essentially an enteric infection, in other words, of the digestive system.

Despite advances of medical science in the mid-20th century, scientists still did not know how the polio virus spread throughout the population or where or when the next outbreak would occur.

The WHO graph above shows Australian statistic on the left and U.S. on the right, the last column in each graph shows that 1951-1953 were the worst epidemics in Australia, as it was in Canada, Denmark, Sweden and the U.S.

The epidemics from 1949 to 1954 were unparalleled in Australia and they peaked in 1951. Almost 16,000 cases were reported to authorities during this period and the highest incidence was in the more heavily populated areas and the newer housing estates where large numbers of families lived. The epidemics became a national problem. Poliomyelitis

officers were appointed in all states and their function was to liaise between the various agencies concerned with the treatment and care of patients.

In 1930 the Sydney Rotary Club took up the challenge of assessing the needs of disabled children in the community and to work towards the goal of providing educational training for disabled children. There was no precedent for this in Australia and no one, be it the Education Department, medical practitioner or hospital, had any idea of the number of disabled children in Australia. When a child was discharged from hospital further help was given only if parents asked for it and many did not know where to go for help.

In their initial survey Rotarians came up against a problem that they had not envisaged and that was the humiliation of many parents of having a disabled child. In Australia, in the 1920's there was a deep sense of shame about having an 'odd' child. Ignorance about where to turn for help for the disabled made an already complex problem into a seemingly insolvable one. Many parents believed that the best and only security for their child was to qualify for an invalid pension which was a pound a week from the age of 16. One of the principle aims of the Society for Crippled Children was to stress to parents the importance of education instead of looking to the certainty of a pension. During this survey Rotarians found hundreds of disabled children living out a lonely existence in the backrooms of their homes; children for whom no constructive rehabilitation treatment was available. Their lives were not documented in the public record; they lived in the shadows, dependent on the goodwill of parents and kin to avoid being sent to an institution.

Using data extrapolated from surveys by Rotarians in the U.S., Sydney Rotarians estimated that in the metropolitan area of Sydney, with its population at that time of one million, there were between two to three thousand disabled children.

In the early 1950's, polio researchers and scientists working in the polio field worldwide discovered that antibodies to the polio virus had been detected in the blood stream of human beings. For many of them it marked the beginning of a dream and that dream was to develop a vaccine that would protect children and their families and their friends from polio. The race was on! It was between Jonas Salk, whose preference was for an injectable killed virus vaccine and Albert Sabin who believed that his oral attenuated (weakened) virus vaccine offered the best chance to rid the world of the disease that appeared to stalk the nation's children. Jonas Salk was the people's hero and Sabin was the scientist's scientist, and the two men utterly loathed each other.

In the early 1940's, Sir Frank Macfarlane Burnet (who was the first Australian to receive the Nobel Prize in 1960) had noted that the age incidence of polio was undergoing what's called a demographic shift to the right, that is, it was shifting from being a disease that mainly affected young children to becoming more common in young adults. No longer was the disease more prevalent in children under 5, polio sufferers were getting older and this was made tragically clear in an epidemic in Wollongong in 1961.

In May 1961 an alarming outbreak of polio began in Berkeley, a suburb of Wollongong in NSW; it reached a peak four months later in September 1961, with almost 200 patients being admitted to Prince Henry Hospital in Sydney. Nearly half the patients were aged under 5 years, two-thirds were under 10 and the remaining one third were aged between 25 and 35 years, and the males outnumbered females by three to one.

From January to June in 1961 there was no Salk vaccine available Australia-wide and May is when the first outbreak occurred in Wollongong. A high proportion of the patients admitted to Prince Henry had not been vaccinated at all or had not received the full three doses. 87% of the 20 patients who died had not been vaccinated and 60% of these were aged over 20. Health officials blamed company complacency for the lower immunisation levels but they did not acknowledge the fact that very little Salk vaccine had been available

in the period immediately prior to the first recorded cases of polio in May of 1961.

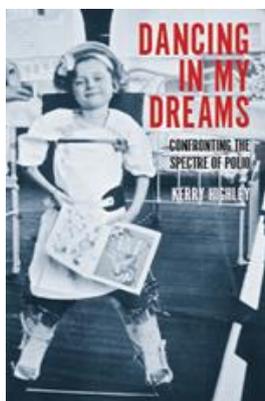
When the Salk vaccine first became available in 1956, priority had been given to vaccinating children under 15 and pregnant women. As noted earlier, Sir Frank Macfarlane Burnet stated that the age incidence of infection was increasing with young adults being affected. Kerry's question, with the benefit of hindsight of course, is whether the authorities in the late 50's and early 60's made adequate provision for or placed enough emphasis on the need to immunise young adults over the age of 15 years.

In the polio epidemic that appeared in 1961 and continued through 1962 many young children in preschools and kindergartens carried the disease home (as carriers, they weren't sick themselves) with disastrous consequences for their parents and their older siblings. An overwhelming majority of those who contracted polio and died during that period were young adults who had not been vaccinated.

Preventing an outbreak of polio in this country relies on maintaining a high level of immunity to polio within the population, preferably above 95%. If that level drops, and it is very low in some parts of northern NSW, then the accumulation of susceptible individuals in the population means that the threat of a polio epidemic rises significantly.

Kerry believes that vaccinating one's children is a community responsibility. She stated that we as a society need to protect those who cannot protect themselves. We should protect those individuals who cannot receive vaccination because of a suppressed immune system, like children and adults who have autoimmune diseases or are undergoing chemotherapy or very young babies who have not been protected by their mother's antibodies.

Kerry drew an analogy between being vaccinated against polio and wearing a seat belt, a seat belt can prevent you from having a serious injury but it won't prevent all injury. What the seat belt will do it reduce the severity of the injury and probably save your life.



Kerry spoke of the photo of the little girl on the cover of her book. The acceptance, the stoicism and the bravery on the face of this little girl is so inspiring, the photo was taken in Fairfield Hospital in 1937, but it is also the face of a child who has been robbed of her childhood and has been forced to grow up too soon and there were many, many children just like her.

Kerry then read a few excerpts of personal recollections from her book, "Dancing in My Dreams, Confronting the Spectre of Polio":

The first is from a woman called Nita who caught polio in the 1937 epidemic in Tasmania.

"After I was admitted to hospital I can remember the doctors in white coats and the nurses and the sisters giving me something to drink and then nothing else. I was evidently unconscious for many days. When I eventually became aware of my surroundings, I was in a big ward with lots of other children. I knew I was in hospital but I didn't know what had happened to me. My arms and my legs felt heavy, I hurt all over and every time anyone walked near my bed the vibration sent pain shooting through my body and tears would run down my face. I couldn't tell anyone because I couldn't speak; my vocal chords were temporarily paralysed. There were all these boxes on the other side of the ward. I'd hear people talking about coffins but I'd never seen one. I thought the boxes were coffins with dead children inside but I couldn't understand why their heads were sticking out. I was terrified. I couldn't ask and I thought that they might put me in one of these boxes."

The next excerpt is about being in a Thomas Splint. A lot of these accounts were written by children who were very young, probably up to the age of about 10.

"I don't know who Thomas was but he certainly thought up a cruel and frightening treatment. The splint was like a wire frame that I was tied into day and night so that I couldn't move. My arms were stretched out like on a cross and my legs were apart. I couldn't move my head. There was a hole in the frame below my bottom to go to the toilet. It was so embarrassing. I was cold all the time from the metal but I wasn't allowed to complain. I spent a long time tied into this thing, staring at the ceiling, and unable to move at all."

The last excerpt is from Val Heath, an Australian, she had an operation to try and straighten up her spine at aged 18.

"They cut a hole in the plaster at the back and they put in a turn-buckle. It became a torture rack; don't think I have ever gone through such pain. Every morning the doctor would turn the screw and as he turned it I twisted and stretched. The pain was shocking. After 4 months I had stretched 6" and my spine was pretty good. So then they operated and cut some bone from my left shin and put it down one side of my spine. I thought that was it but then three weeks later they did the other side.

I was happy in hospital."

Three recollections from people in the initial stage when they were first admitted to hospital and wondered where the hell they were and what's was going on and then going into the Thomas splint. Some people had surgery and others didn't.

Photos are reproduced with permission.

Polio Health and Wellness Retreat – Body, Mind and Spirit – 26 to 29 October

What are you doing right now to keep your body, mind and spirit healthy? Our upcoming Health and Wellness Retreat will allow you to zone out of your everyday and zone in to your body, mind and spirit with your fellow polio survivors and the wider post-polio community.

Polio Australia's seventh Health and Wellness Retreat is being held on the beautiful Sunshine Coast in Queensland between Thursday 26th and Sunday 29th October 2017.

The knowledge gained during these Retreats has not only assisted participants to better manage their own condition, but is also being shared with their health professionals, thereby facilitating improved care for other patients present with the Late Effects of Polio.

The heavily subsidised Registration Fees start at \$350.00 per person, and include three nights' accommodation, all meals, workshops, clinical assessments, and activities.

So if you are ready for some summer sunshine and want to improve your wellbeing, now is the time to book your place! Please head to www.polioaustralia.org.au/retreat-2017/ for more information, and to download Registration Forms.

Maryann Liethof

National Program Manager
Polio Australia Incorporated

Promoting Positive Solutions

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QUESTION: *I was recently asked why I never attended post-polio meetings unless I speak and why I didn't ask questions of the internet groups of polio survivors. I immediately knew the answer – those situations make me feel vulnerable, so I avoid them. Is this a healthy way of coping?*

Response from Stephanie T. Machell, PsyD:

Dr Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

There's no one healthy way of coping. Some people thrive on information and group interactions. Others don't. I know many polio survivors who don't attend support groups. Usually this is because they have experienced groups that became negative, either judging/scapegoating certain members or spending the majority of group time complaining and never discussing solutions. Groups like that, whether in person or online, would make anyone feel vulnerable!

Limiting your exposure to information can be healthy. It's important to know your limits so you don't become overwhelmed by the volume and/or repetition of information. Knowing groups and meetings cause you to feel vulnerable means you can control your exposure to them.

Then again, it depends on what you mean by vulnerable. Vulnerability, as in openness to experience and/or others, can be a way of making connections. It requires trust that your experience and limits will be respected. Again, if this hasn't been your experience in groups it is understandable why you wouldn't want to be vulnerable in them.

If you mean that the information you receive, or the condition of others attending the group, bring up fears about the future that cause you to feel personally vulnerable, avoidance may still be healthy — to a point. I often tell my clients that the “healthiest” stance for a polio survivor is a combination of acceptance and denial, in varying proportions. If your avoidance keeps you from dealing with important or necessary issues, meeting people who could be friends and allies, or from learning about things that could improve your quality of life, it isn't helpful, and it probably isn't healthy.

Rather than avoiding groups altogether, it might be useful to consider what you lose by not going, and what you might gain by participating. If choosing to go only when you are presenting helps you to feel in control, and lack of control is part of what makes you feel vulnerable, is there another way to control the situation?

For example, you might ask questions of trusted others in private messages rather than exposing yourself to the entire online forum, or only attend meetings where information you need will be shared. You could sit in the back and leave if things feel too overwhelming, or take breaks and return. If you're worried what others will think, you can develop a “sound bite” speech to explain that you are pacing yourself/practicing good self-care/drank too much coffee and needed the bathroom/in denial (if the person asking is a fellow polio survivor, he/she will likely laugh).

It's also all right to decide groups really aren't your thing and you'd rather not waste precious energy on dealing with them. Those who use groups and forums aren't better adjusted or coping better—they're coping differently. Obtain information in ways that make you comfortable and you will be coping just fine!



The Role of the Primary Care Physician in the Life of a Polio Survivor

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William DeMayo, MD, Summit Medical Rehabilitation, PC, Johnstown, Pennsylvania

On each of my several trips to Post-Polio Health International conferences, as well as on my recent three-week lecture circuit in Australia, I have been amazed at the number of individuals who see my specific expertise as “the missing piece” in their future health, yet their local therapists and primary care physicians (PCP) seem to be relegated to some distant and less important role.

While I appreciate the importance of specific expertise in this sub-specialty area, I often find myself trying to bring folks back to their local resources. In my opinion, regardless of expertise, it is local therapists and PCPs that can have a much bigger role in long-term health.

The most obvious reason to conclude this is that a polio survivor’s health is not solely dictated by their history of polio. They are just as susceptible to the same medical conditions as everyone else. In fact, for some, a relatively sedentary life will make them more susceptible.

The following conditions each have an incidence of at least 10% in those over 65 and ALL ARE ON THE RISE in this age group:

- High Blood Pressure (55%)
- High Cholesterol (45%)
- Diabetes (20%)
- Cancer (>10%)
- Mental Illness (>10%)
- Back Problems (>10%)

Multiple other conditions pose a significant threat of disability as we get older:

- Obesity
- Coronary Disease/ Congestive Heart Failure
- TIA/Stroke
- Arthritis
- Bladder and Bowel difficulties
- Infection
- Lung disease
- Kidney disease

Most individuals develop MULTIPLE chronic conditions as they age:

- For 65-75 year olds
 - >20% had a chronic condition
 - >50 % had two-four chronic conditions
- This trend increases after 75 years of age with >20% having more than five chronic conditions.

Primary care physicians are the “go-to person” for nearly all the above conditions yet, somehow, their role seems to be minimized by many polio survivors.

It has been my sense that this is, at least in part, due to a frequent “disconnect” that occurs when the issue of polio or post-polio related issues come up. Most PCPs willingly admit to a lack of expertise in this area and, sometimes, this creates a dynamic that their opinion on other matters is also downgraded. In fact, from my standpoint, it is unreasonable to expect that a PCP have extensive post-polio knowledge.

Rather than downgrading the PCP opinion on other matters, it is my opinion that polio survivors are better off being unusually grateful for the PCP. Since the vast majority of physicians went into medicine for good reasons, a statement like, “*I really need your help with ...*” goes a long way. Consider comments like “*I really appreciate your keeping such a close eye on my blood pressure*” or “*My polio slows me down enough, I’m really glad that you help me tightly control my diabetes, so I won’t have complications that worsen my disability*”. These comments will increase the connection rather than allow a disconnection that may result when a PCP is not familiar with concerns that relate to adaptation to slow progress of weakness and chronic disability (aka PPS).

Having said all of the above, most of us have noticed that medicine has been changing. There may be PCPs out there that just won’t engage. In this case: find another PCP. One physician’s lack of interest should not dictate a polio survivor to poor future health.

Polio survivors, as a group, have a long history of focusing on goals and making things happen despite adversity. It is surprising that in dealing with the healthcare system, some can become passive or even fatalistic. In my opinion, the same “Can Do” attitude can be applied to assuring optimal health care by working with the healthcare system to insure that it meets their needs.

The stakes are too great not to address the issue. If developing polio is seen as a strike, and post-polio is a second strike, one more unmanaged (yet preventable) chronic condition could be the last strike leading to severe disability and loss of independent living.

In this light, one can say that the role of the PCP becomes even greater, not less, for aging polio survivors.

From 2004–2012, a series of conference calls was held for post-polio clinic directors. The calls were chaired by William DeMayo, MD. The PowerPoints and summaries of some of the calls are posted on Polio Place as PHI’s Post-Polio Clinic Directors Network at www.polioplace.org/phis-post-polio-clinic-directors-network.



A Sister Remembers

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By **Mary Navarre**, OP, Grand Rapids, Michigan

When Joan Headley, PHI Executive Director, asked me to be on a panel of family members of polio survivors at the conference in St Louis, I was hesitant to do so as it was, and still is, difficult to talk about my life with my sister who contracted polio at the age of 6 – and even more so to speak about her death four years ago at the age of 64. Yet, I thought it might be helpful to others who are survivors and those who love them. And so I gathered some thoughts on the topic and went to the conference. I soon found myself in a room at the hotel with two other members of the panel, one was the daughter of a survivor and the other was the husband of a survivor.

As the polio survivors, their spouses, siblings and adult children began to fill the room, I became aware of enormous amounts of fatigue, pain and confusion in the air. And this was not among those using wheelchairs. This was among the significant others of those who had survived polio. After the three of us spoke, questions were asked that revealed puzzlement, mixed messages, anger and hurt. Some of the survivors had overcome many of the physical limitations they had experienced at the onset of the disease and were now experiencing what seemed like a recurrence.

Who wouldn't be angry? Spouses may not have known the person when he or she contracted polio originally, and they were now puzzled at what was happening. Some survivors appeared to be reacting out of resentment and anger that they were now losing the independence they had fought so hard to achieve, and sometimes they expressed feelings of hostility toward their significant others who didn't seem to GET IT. For example, a husband said, "If I ask her if she needs help she says, 'no,' then, she blames me for not seeing that she does need more help."

I can relate to this reality as my own sister was fiercely independent, yet as she became more dependent on assistive devices, oxygen and ventilator, her rage was sometimes vented toward those with whom she felt most safe – her family. Understanding this helps relieve some of the sting, but is not the whole answer.

Outside Help May Alleviate Stress

My sister and I learned through trial and error that we needed outside help to enable us to negotiate the treacherous waters of the post-polio world; she needed to hire a lot more done for her along the lines of physical help, domestic duties, transportation and home health aides so that we could be sister to each other, and I would not be in the role of nurse, cleaning lady or chauffeur whenever we were together. Cost was an issue, of course, but eventually there was no other choice and with some assistance (albeit minimal financial help from government programs like Independent Living), the stresses were alleviated – somewhat.

From the very beginning, our relationship was one of big sister (me) and little sister (her) as I was 9 years old and she just 6 when in 1952, polio dropped into our family's life like a bolt out of the blue. We have three brothers who were part of the picture – each of them coped with the dynamics in his own way; but that is a story for them to tell.

My parents were heartbroken as they watched their darling, red-haired, lively 6-year-old struggle to breathe and move and live. And we, the siblings, were baffled completely. In that day and time and place, children were not told much of anything and we were left to figure it out for ourselves.

My own response was to try to make it up to my sister that she could not and would never walk again. I felt guilty for walking and doing things she could not do. I always looked out for her and tried to flatten the bumps and smooth the way. Although we each came to lead our own very productive and fairly happy lives, I still to this day survey new terrain for accessibility. Nice restaurant! Hmm. Steps at the front entrance. No ramp. How does a person in a wheelchair get in?

Eventually, I learned that I could not make it up to her, but I could be her sister. I could walk beside her even if I could not be the fixer-upper and the problem-solver – although I must say I can leverage a wheelchair just about anywhere and coax a reluctant battery to kick in when the wind chill is well below zero.

Counseling and Support Groups Are Useful

I think in some cases, a family systems counselor could have helped all of us negotiate this terrain, and support groups for both relatives and survivors could be useful in airing the emotional baggage and strategizing on how to make life better for all concerned.

Polio doesn't happen to one person; it truly does happen to an entire family. In fact, in the 1940s and 1950s, it happened to our entire nation, and that has had its effects too. Those who **survived** the polio epidemic tended to be lionized as heroes (millions had died over the decades), and of course President Franklin D. Roosevelt was the epitome of the polio hero who pulled the nation through the great depression and never appeared the least bit stressed. Hugh G. Gallagher's story, *FDR's Splendid Deception*¹, is a well named book as it depicts the intense efforts he, his family and staff took to conceal his disability from the public.

But lionizing a survivor can be an added burden. Polio survivors are not lions, nor victims, nor heroes, nor saviors – neither are their significant others any of these things. We are people, interdependent, sometimes loving, sometimes really pains in the back sides of one another.

My sister had a favorite poem which I would like to quote here as it is just two sentences in length, but captures much of our lives together then and even now in this new day and way of being family.

*We sat talking in the summer sun,
lazing on the swing
and as it swung,
we moved from light to shadow,
weaving strands
of memories and plans.*

*And so we added length
and strength and color
from the varied fiber
of our lives,
knowing that the parts
may fray and ravel,
but the fabric
of our family survives.²*

1. Hugh Gregory Gallagher. *FDR's Splendid Deception: The Moving Story of Roosevelt's Massive Disability and the Intense Efforts to Conceal it from the Public*. Vandamere Press, 1999.

2. Genevieve Smith Whitford. "Reunion" from *Queen Anne's Lace and Other Poems*. Harp Press, Madison, Wisconsin, 1982.



The Black Holes of Memory

By Fran Henke

Reprinted from Polio Perspectives, Inform, Winter 2016, and with permission from the author

As a polio survivor in the depths of Community Health, the question is often asked, 'tell me about your childhood?'. My answer, is as it always will be, 'I remember nothing'.

Some polio survivors remember every moment of treatment, the isolation at Fairfield or Frankston, their memories extending then to the schooling years. 'Ordinary' people have

stories of family holidays and adventures, friends from kinder and school. I remember nothing.

Freud's work on defence mechanisms in children was mentioned by my husband. Sometime later a community health nurse introduced me to the concept of 'childhood amnesia'. So I went exploring looking thoroughly into them both.

In my search I came across an article: '*Emotional trauma & childhood amnesia*' by Rhawn Joseph PhD of the Brain Research Laboratory (2003). His findings read, "*among the general population childhood amnesia (CA) has its offset at around age 3.5 with females forming their first recallable memories earlier than males*". He then went on to discuss the topics of TA (trauma or abused).

Rhawn Joseph's explained "*because negative and repetitive stressful experiences disrupt memory and can injure memory centres such as the hippocampus and amygdala, and since adults who were traumatized or abused (TA) during childhood reportedly suffer memory disturbances, it was hypothesized that those with a history of repetitive instances of early trauma, might suffer from a lengthier period of childhood amnesia and form their first recallable memories at a later age as compared to the general population*".

For me, the words of Rhwan Joseph could not be more true as I found working on '*Iron Wills – Victorian Polio Survivors Stories*' (2012) triggered memories (or did they belong to others?) of tough painful treatments, physios with big hands, doctors with whom I held adult conversations, of long periods alone, books were my best friends.

One painful flashback came a couple of years later after being put in a pressure suit to help circulation in the polio leg. Instinctively I begged the therapist not to turn out the lights or close the door. She did both. As part of the ensuing panic attack (I never have panic attacks) images of being tied into the Double Thomas, given aspirin and the lights turned out flooded back. I cried all the way home.

Another ugly piece of baggage involved being exhibited naked as a child for doctors, nurses, students' edification, leaving me and others as adults with problems undressing at swimming pool change rooms, fitting rooms, surgeries etc. I have been able to swim regularly only by wearing bathers to the pool and driving home in the wet ones to shower privately. I can only hope children in health settings be treated more respectfully today.

As I researched further into defence mechanisms and denial I found the following citation by Dr T Manichander to be most true.

"Denial is the refusal to accept reality or fact, acting as if a painful event, thought or feeling did not exist. It is considered one of the most primitive of the defence mechanisms because it is characteristic of early childhood development. Many people use denial in their everyday lives to avoid dealing with painful feelings or areas of their life they don't wish to admit. For instance, a person who is a functioning alcoholic will often simply deny they have a drinking problem, pointing to how well they function in their job and relationships". 'Psychology of the Learner'

So many polios have not come forward to learn about PPS, to share self-management advice of which most health professionals are ignorant. Come out please, we are all here for each other. The shame has gone. We are fighting for proper care at last.

I swore off any kind of therapy after the pressure suit ordeal. But inevitably, the need came for me to see a chiropractor. I found one who worked on unravelling nerve endings rather than bone crushing. I told him about my allergy to doctors, physiotherapists, and hospitals. "*Ah, disassociation*", he commented, swiftly fixing the unstable pelvis, evening up my legs, promising to restore me to pre post-polio health and clear fog brain. This largely has

happened – if I treat myself respectfully as a 72-year-old person of course.

But disassociation? Sounded so harsh and impersonal!

“Disassociation is when a person loses track of time and/or person, and instead finds another representation of their self in order to continue in the moment. A person who dissociates often loses track of themselves and their usual thought processes and memories. People who have a history of any kind of childhood abuse often suffer from some form of dissociation. In extreme cases, dissociation can lead to a person believing they have multiple selves.”

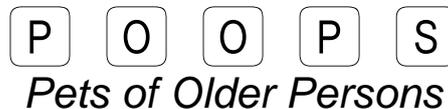
Many polios are in denial, not ‘fessing up’ to having had polio when experiencing new pain, falls, respiratory problems, resulting in lack of proper management for Post-Polio Syndrome. While there are still black holes of memory, I have come to the comfortable understanding that we don’t need to remember everything about childhood, about polio or other formative experiences. Troubling thoughts may surface. Look at it, learn from it, and delete, delete, delete. Live for the joyous day.

Last word from Dr Andrew Sinclair, Manager of Psychology, Independence Australia

I encourage people to be open and curious to their experience, both pleasant and unpleasant experiences – after all we are the experiencer not our experiences (put another way we are not our thoughts we are the thinker!)

If I have read Fran’s journey correctly, she encourages others to note the experience non-judgmentally and then let it go – the perfect recipe to not get caught up in it.

Remember – you are not your memories – you are the person remembering!



A pet can mean everything to an older person, especially if they are socially isolated. Our Pets of Older Persons (POOPs) program helps these people by looking after their pets in times of crisis. Our aim is to keep pets and their elderly owners happy, healthy and together in their own homes for as long as possible.

We can assist people 65 years of age or older with temporary foster accommodation and/or emergency boarding of the pet should the owner require medical treatment, respite or other assistance. We also help with veterinary treatment, assist with pet grooming, and conduct home visits to assist with basic pet care. These services are also available to those who cannot access veterinary assistance due to age and disability, have no relatives or friends willing to help care for their pet or for palliative care patients of any age who are socially isolated.

As with all RSPCA services, POOPs does not receive any ongoing government funding, so relies on your generosity to continue to help people and their pets. Volunteers for the program are also welcome. Volunteers can help with dog walking, cat feeding, assistance with transport to and from the vet, in home assistance and grooming or be a foster carer by providing temporary emergency home care for short periods of time.

For more information, please email <poops@rspcansw.org.au> or phone (02) 9782 4408
www.rspcansw.org.au/our-work/programs-community-services/pets-for-older-persons



Member, Mona Dwyer from Young NSW has a power chair for sale



“The Shoprider power chair was purchased second hand from Scooter City at Cowra in 2004 as a ‘stand by’ chair for emergencies. It has had very little use and only used indoors. The batteries lasted for ten years and were replaced in 2014. The chair is in excellent condition. The asking price is \$1,500.” Contact Mona on 02 6382 5224.

Member, Shirley Roach has moved to Boonah QLD and wrote to us about a foot massager

“The Occupational Therapist here is helping me a lot, especially with my painfully cold feet and legs. I now have a **Visage Foot Massage** machine to warm my feet. I wear extra warm socks (2 pairs) and put my feet on the machine (with socks on) and the massage and heat really helps. The Village bought it. It could help others.”



2017 Polio NSW Seminar Program

Saturday 2nd December	Burwood RSL Shaftesbury Road Burwood	Polio NSW AGM & Seminar Speaker to be confirmed
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Management Committee - Executive Members Contact Details

Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
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Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641

Committee Members (for contact details please ring or email the Network Office):

Charles Anderson, Anne Buchanan, Nola Buck, Ella Gaffney, Anne O'Halloran, Di O'Reilly and John Tierney

PNSW Office and Other Contact Details

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